DOCUMENT RESUME

ED 375 534 EC 303 370

AUTHOR	Troccoli, Karen B.
TITLE	Fetal Alcohol Syndrome: The Impact on Children's Ability To Learn. Occasional Paper #10.
INSTITUTION	National Health/Education Consortium.
SPONS AGENCY	Prudential Foundation, Newark, N.J.
PUB DATE	Jul 94
NOTE	41p.; Produced in collaboration with the Children of Alcoholics Foundation.
AVAILABLE FROM	National Health/Education Consortium, Institute for Educational leadership, Suite 310, 1001 Connecticut Ave., N.W., Washington, DC 20036 ($5).
PUB TYPE	Information Analyses (070) -- Viewpoints (Opinion/Position Papers, Essays, etc.) (120)
EDRS PRICE	MF01 Plus Postage. PC Not Available from EDRS.
DESCRIPTORS	Academic Aptitude; Biological Influences; Change Strategies; Congenital Impairments; *Educational Strategies; Elementary Secondary Education; Environmental Influences; Family Programs; *Fetal Alcohol Syndrome; *Incidence; *Intervention; Misconceptions; Prenatal Influences; Preschool Education; *Prevention

ABSTRACT

This paper provides information on the incidence and prevalence of alcohol-related birth defects, the human and economic costs of fetal alcohol syndrome (FAS) and fetal alcohol effects (FAE), and examples of prevention and intervention strategies that can help reduce the occurrence of and ameliorate the consequences of FAS/FAE. It discusses the interrelationship of biological and environmental factors in affecting vulnerability to exposure and the implications for educating children born with FAS/FAE from infancy through adulthood. Prevention and intervention strategies include changing the drinking behavior of pregnant women through education and intensive treatment, monitoring high-risk infants' developmental progress, providing early intervention for children with FAS/FAE, and helping families learn how to cope with the demands of raising a child with FAS/FAE. Recommendations offer action steps to combat FAS/FAE, including general recommendations, recommendations targeting women, and recommendations targeting children. The paper concludes that preventing FAS/FAE through public education and treatment of pregnant women for alcohol or other drug dependencies is needed, and until that is achieved, carefully structured intervention programs for children with FAS/FAE must be developed. The paper includes a discussion of 10 common misconceptions about FAS/FAE and a list of eight resources for additional information on FAS/FAE. (Contains approximately 50 references.) (JDD)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

EC

NATIONAL

HEALTH/EDUCATION

CONSORTIUM

ED 375 534

Fetal Alcohol Syndrome: The Impact on Children's Ability to Learn

National Health/Education Consortium
Occasional Paper #10

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)
☑ This document has been reproduced as received from the person or organization originating it.
☐ Minor changes have been made to improve reproduction quality.
• Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

"PERMISSION TO REPRODUCE THIS MATERIAL IN **OTHER THAN PAPER COPY** HAS BEEN GRANTED BY
C. A. Foley
TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)"

BEST COPY AVAILABLE

EC 303370

National Commission to Prevent Infant Mortality

Institute for Educational Leadership

Fetal Alcohol Syndrome: The Impact on Children's Ability to Learn

National Health/Education Consortium
Occasional Paper #10

Produced in collaboration with the
Children of Alcoholics Foundation

Written by

Karen B. Troccoli

This occasional paper series is supported by the **Prudential Foundation**. Additional support for *Fetal Alcohol Syndrome: The Impact on Children's Ability to Learn* was provided by **The Children of Alcoholics Foundation**.

The occasional papers published by the National Health/Education Consortium and supported by the Prudential Foundation include:

Healthy Brain Development: Precursor to Learning
Occasional Paper #1

A Practitioner's Perspective on the Interrelationship of the Health and Education of Children
Occasional Paper #2

Cocaine-Exposed Children: A Growing Health/Education Issue
Occasional Paper #3

At Risk Does Not Mean Doomed
Occasional Paper #4

Health/Education Collaboration: Insights Into Six Field Activities
Occasional Paper #5

The Poisoning of America's Children: Lead Exposure, Children's Brains, and the Ability to Learn
Occasional Paper #6

Eat to Learn, Learn to Eat: The Link Between Nutrition and Learning in Children
Occasional Paper #7 (also published as an NHEC special report, listed below)

Children's Mental Health and Their Ability toLearn
Occasional Paper #8

School Nursing: Trends for the Future
Occasional Paper #9

Fetal Alcohol Syndrome: The Impact on Children's Ability to Learn
Occasional Paper #10

Additional NHEC publications include:

Crossing the Boundaries Between Health and Education

Creating Sound Minds and Bodies: Health and Education Working Together

Bridging the Gap: A Health Care Primer for Education Professionals / Bridging the Gap: An Education Primer for Health Professionals

Eat to Learn, Learn to Eat: The Link Between Nutrition and Learning in Children

Florida's Youth/Florida's Future

Texas' Youth/Texas' Future

Table of Contents

Foreword	v
Introduction	1
What are Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE)?	2
How Big is the Problem?	3
What is the Financial Toll of FAS?	5
What is Known About Prenatal Exposure to Alcohol?	5
What are the Implications for Educating Children Born with FAS/FAE?	8
Prevention and Intervention Strategies	10
Recommendations	20
Conclusion	23
10 Common Misconceptions about FAS and FAE	24
Resources for Additional Information	26
References	27

Acknowledgements

This report could not have been written and produced without the assistance and support of several people. The National Health/Education Consortium, the Children of Alcoholics Foundation and Karen B. Troccoli would like to thank the members of the review committee for sharing their time and expertise: Patricia Tanner Halverson, Fetal Alcohol Syndrome Project Director; Patricia Munter, National Organization on Fetal Alcohol Syndrome; Linda Asmussen, Chair, Healthy Mothers, Healthy Babies Substance Use in Pregnancy/HIV/AIDS Committee, American Academy of Pediatrics; and Lucy Barry Robe. We would also like to thank Philip May, Director, Center on Alcoholism, Substance Abuse, and Addictions (CASAA) at the University of New Mexico for his assistance.

The National Health/Education Consortium is grateful to the Prudential Foundation for its ongoing support of our efforts to promote the education and health of our nation's children. In addition, the Children of Alcoholics Foundation would like to thank the Prudential Foundation for its generous financial support which made collaboration on this valuable document possible.

Foreword

Fetal Alcohol Syndrome is a dual family tragedy because it lasts a lifetime and because it is entirely preventable. And therein lies the hope: with education, help, and intervention by educators and health care professionals, women considering pregnancy, can be informed about the critical need to abstain from using alcohol.

This report on the effects of mothers' drinking while pregnant on their children is designed to provide health care professionals and educators the information they need to help youngsters born with Fetal Alcohol Syndrome (FAS) or Fetal Alcohol Effects (FAE). It addresses the importance of identifying these children early and providing them services tailored to their special needs. Only through early and appropriate intervention will these children reach their full potential.

Yet few health care, education, and social service professionals receive training or information about the often devastating impact of maternal drinking during pregnancy. And they are not alone. In addition to professionals, parents, siblings, and other relatives also need information, materials, and even counseling about a child's ability to learn and to thrive both in childhood and throughout their lives. Family members often do not know how to cope with these youngsters, or how to help them.

With additional research lies a promise of hope. We must continue to learn about FAS and FAE, and the programs these children need. Because FAS and FAE were only recently identified, there is still much missing information. Research can provide the answers necessary to enhance the programs, services, and education these children receive.

The National Health/Education Consortium and the Children of Alcoholics Foundation are pleased to present this vital report for educators, health care professionals, those involved in public policy, and others in key positions to make improvements in children's lives. We hope it will encourage and inspire them to reach out to families to prevent maternal drinking during pregnancy, understand the devastating effect of FAS/FAE, and show them how to help children have happier and more successful lives.

Sincerely,

Tamara Lucas Copeland
Director,
National Health/Education
Consortium

Migs Woodside
Director,
Children of Alcoholics
Foundation

Fetal Alcohol Syndrome: The Impact on Children's Ability to Learn

by Karen B. Troccoli

Introduction

The learning potential of many children is impaired long before they walk through the school-house door. Prenatal alcohol exposure is one key culprit.

Recent years have witnessed a surge in concern about maternal drug use during pregnancy and its effects on offspring. Most front-page stories and news magazine shows have focused on "crack babies" (babies exposed to crack-cocaine before birth) and boarder babies (babies left as "boarders" at hospitals by mothers who are drug-addicted and unable or unwilling to care for them). Yet drug use during pregnancy is neither a new phenomenon, nor limited to illicit drugs. Alcohol is the drug of choice for many women. According to the *National Household Survey of Drug Abuse: Population Estimates 1992*, 4.1% of women used an illicit drug in the past month, while 40% used alcohol. Over the past two decades, alcohol exposure in utero has been increasingly identified as a leading cause of mental retardation and the cause of patterns of birth defects known as Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE). This paper, the tenth in the National Health/Education Consortium's (NHEC) series of "Occasional Papers," examines alcohol use during pregnancy in the context of children's health and ultimate learning potential.

The first of the National Education Goals states that by the year 2000, "All children in America will start school ready to learn." This will require that they be as healthy as possible. However, the learning potential of many children is impaired long before they walk through the school-house door. Prenatal alcohol exposure is one key culprit.

This paper includes information on the incidence and prevalence of alcohol-related birth defects, the human and economic costs of FAS/FAE, and examples of prevention and intervention strategies that can help reduce the occurrence of and ameliorate the consequences of FAS/FAE. That FAS and FAE are totally avoidable through the elimination of alcohol consumption during pregnancy indicates the importance of front-end, prevention efforts. To that end, universal access to appropriate, comprehensive and affordable health and social services for all women of childbearing age is critical. Short of total prevention of FAS/FAE, however, intervention strategies are needed that take into account

the cognitive and behavioral deficits common among infants, children and adults with FAS/FAE, and that can help them reach their full potential.

NHEC developed this paper in collaboration with the Children of Alcoholics Foundation to provide educators, health professionals, program administrators, policymakers, advocates, and others working with children and their families with an overview of how alcohol use during pregnancy, in general, and FAS, in particular, affect children's well-being and their ability to learn. It is hoped that this paper will raise awareness about the impact of FAS and FAE on the health/education connection and spur educators, health professionals and others to collaborate in efforts to address the needs of FAS/FAE children and their families.

What are Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE)?

The bottom line is that FAS/FAE only affect children of women who consume alcohol during pregnancy.

Studies have established that alcohol is a physical and behavioral teratogen, that is, an agent that produces birth defects in offspring in utero. In 1973, researchers Kenneth Jones and David Smith, at the University of Washington in Seattle, identified and named Fetal Alcohol Syndrome (FAS) as a specific pattern of birth defects observed in children born to alcoholic mothers. However, since then it has been observed that even women who drank occasionally during pregnancy have had children with FAS or FAE. Why the consequences of prenatal alcohol use vary from person to person is unclear, although factors such as dose and timing may play a role. The bottom line is that FAS/FAE only affect children of women who consume alcohol during pregnancy.

Prenatal alcohol exposure can produce a variety of effects that range in severity from overt physical anomalies and mental impairment, including mental retardation, to more subtle cognitive and behavioral dysfunctions (NIAAA 1993). To satisfy a diagnosis of FAS, three specific conditions must be present:

1) **Prenatal and postnatal growth retardation**. Although some FAS infants are born prematurely and would, therefore, be expected to be small, one of the consequences of FAS is that the infant is small for gestational age. Children with FAS grow more slowly than 90% of other children and, although development is progressive, the deficit is permanent (Morse 1993).

2) **Central nervous system (CNS) dysfunction**. Small head circumference, mental retardation, difficulties in balance, and poor coordination are the most overt symptoms of CNS damage. Other signs include learning disabilities, hyperactivity with reduced attention span, and difficulty modifying behavior in response to experience. Abnormalities are also found in the vision and hearing systems, which can have implications for learning.

3) **Facial abnormalities**. Typical characteristics include a small head with short eye openings, a thin upper lip, an elongated flattened midface, and a smooth area from the base of the nose to the upper lip (philtrum) (NIAAA 1993). Teeth often grow abnormally and ears may seem large, low-set and/or deformed.

In addition to these three conditions, many other birth defects have been identified in FAS children. Examples range from the mild (abnormal skin creases on the palms) to the severe (heart defects and spinal abnormalities) (Blume 1992). For those individuals who have only one or two of the characteristics of FAS, the terms Fetal Alcohol Effects (FAE) or Alcohol-Related Birth Defects (ARBD) are often used.

How Big is the Problem?

In discussing the incidence and prevalence of FAS/FAE, it is important to consider that underestimation and underreporting are commonplace.

Unlike many other health conditions and diseases, no single FAS/FAE reporting system has been established to collect statistics. The Centers for Disease Control and Prevention's (CDC) Birth Defects Monitoring Program (BDMP), a national program to monitor congenital malformations, includes data on FAS cases among newborns based on participating hospitals' discharge data. However, the CDC believes that BDMP underestimates the true incidence of FAS (CDC 1993). The CDC has also funded several FAS research and state prevention projects in an effort to improve the current methodology for ascertaining the incidence and prevalence of FAS. For example, the CDC, the Alaska Department of Health and Social Services, and the Indian Health Service linked and analyzed data from state sources (such as birth and death certificates and Medicaid claims), an Indian Health Service case file, and a private pediatric practice case file. The studied population included mostly Alaskan Natives, and an FAS rate of 2.1 per 1,000 was reported. The CDC and the University of New Mexico, Center on Alcoholism, Substance Abuse and Addictions (CASAA) are working on a population-based FAS epidemiologi-

cal research project. The five-year initiative seeks to implement a system of population-based screening for FAS, establish and monitor the prevalence of FAS, determine maternal risk factors for FAS, improve FAS recording for infants and children, and provide technical assistance for evaluating prevention efforts throughout the state. Further improvements in the collection of FAS and FAE data will bolster understanding about their impact and be key in spurring responsive action.

Several other factors contribute to underreporting as well. Health care providers often fail to diagnose FAS at birth since few are adequately trained to recognize it. Moreover, facial features are difficult to identify in the neonatal period, and CNS dysfunctions, including mental retardation, may not be identified until years later. Evidence of missed diagnoses was documented in a study in which medical records of 40 infants born to 38 mothers known to have drunk heavily during pregnancy were reviewed. Investigators found that medical personnel failed to diagnose alcohol-related birth defects in any of the children who were later identified as having FAS or FAE, even though maternal alcohol use was documented in the records (Little 1990). It is likely that cases of FAE are underreported even more so than FAS cases, given FAE's more subtle manifestations and the lack of specific criteria for a diagnosis.

FAS is estimated to occur in 1.9 per 1,000 live births, or approximately 7,000 cases per year in the United States (Abel & Sokol 1987). This makes FAS the leading known preventable cause of mental retardation (Abel & Sokol 1986).

Despite the lack of a dependable methodology, attempts to quantify the extent of FAS and FAE have resulted in some useful estimates. FAS is estimated to occur in 1.9 per 1,000 live births, or approximately 7,000 cases per year in the United States (Abel & Sokol 1987). This makes FAS the leading known preventable cause of mental retardation (Abel & Sokol 1986). FAE is believed to occur three to four times as often as FAS (Abel & Sokol 1987). FAS/FAE occur in children from all ethnic groups and socioeconomic classes, although rates vary. Among African Americans, the rate of FAS is approximately seven times that of whites (Sokol 1986). While rates differ among Native American communities, rates as high as 10 per 1,000 (May 1983) among some Native American populations and 120 per 1,000 (Robinson 1987) among Canadian Indians have been reported. A study of the incidence of FAS among Native American groups in the Southwestern United States reports rates ranging from 1.3 per 1,000 live births (1/749) to 10.3 per 1,000 live births (1/97) (May 1983). The reasons for higher FAS rates among African Americans and Native Americans are unclear. Interestingly, women in both groups are more likely to abstain from drinking, but a higher proportion of those who do drink tend to do so heavily (May 1994).

What is the Financial Toll of FAS?

FAS/FAE take a heavy toll on society, both in human and fiscal terms. Streissguth (1991) estimates that it costs $596,000 for a lifetime of care for a child with FAS, while the Alaska Office of Alcoholism and Drug Abuse puts the cost at $1.4 million (Anderson 1992). Overall national cost estimates for FAS range from $75 million to $3.2 billion annually (NIAAA 1993).

Overall national cost estimates for FAS range from $75 million to $3.2 billion annually (NIAAA 1993).

The variations in cost estimates are due to difficulties estimating the prevalence of FAS/FAE, as well as differing cost components, such as medical treatment, residential care and lost productivity, used in each study. For example, one study places the annual cost of treating the birth defects associated with FAS at $1.6 billion. It attributes 80% percent, or $1.3 billion, to residential care and support services for mentally retarded persons over age 21 with FAS-related impairments. The cost of neonatal intensive care for growth retardation due to FAS accounts for $118 million (7%), while full-time residential care for severely mentally retarded individuals under age 21 accounts for $110 million (7%) of the total (Rice et al. 1990). Regardless of the exact figure, it is clear that alcohol-related birth defects cost society plenty.

What is Known About Prenatal Exposure to Alcohol?

Not all pregnant women who drink have children with FAS or FAE, and not all children with FAS or FAE are alike. Studies suggest that biological and environmental factors, coupled with the amount and timing of prenatal alcohol intake, affect vulnerability to exposure (NIAAA 1993). Understanding the interrelationship between these factors is critical to developing appropriate and responsive prevention and intervention strategies.

When consumed during pregnancy, alcohol crosses the placenta. However, exactly how it affects the fetus is not well understood. Processes being studied include the direct toxic effect of alcohol on tissues; toxic effects of acetaldehyde, the substance that alcohol is initially metabolized into, which is highly toxic to cells; interference with fetal nutrition; interference with fetal oxygen supply; effect on the prostaglandin system, which is important throughout pregnancy to fetal development; and interference with growth-signaling chemicals (Blume 1992).

The effects of drinking during pregnancy appear to be correlated with timing and dose. Studies suggest that first trimester exposure is associated with organ and musculoskeletal anomalies (Osborn 1993), whereas third trimester exposure is most likely to affect central nervous system development (Morse 1993). The brain appears to be sensitive throughout all trimesters to both acute and chronic alcohol exposure, although various regions of the brain may have different thresholds and critical periods of susceptibility (NIAAA 1993). In regard to dose, the risk to the fetus increases in both incidence and severity with the amount of alcohol consumed (Morse 1993). However, establishing exactly how much alcohol is too much and when the fetus is at greatest risk have proven difficult. Animal studies indicate that binge-like exposure to alcohol may be more harmful than exposure to the same or greater quantities of alcohol spread out more evenly over time (Bonthius & West 1990). Yet, any woman who consumes alcohol during pregnancy risks bearing a child with FAS/FAE.

Other factors that appear to affect offspring's susceptibility to alcohol include increasing age and parity of the mother, with the latter acting independently of the former. The risk that a younger sibling of a child with FAS will also have FAS is 77%, assuming equal or higher consumption of alcohol during the second pregnancy (Abel 1988). Individual differences in maternal metabolism of alcohol during pregnancy and genetic factors that affect vulnerability to drinking may also play roles (NIAAA 1993). Other drug exposures during pregnancy also can affect the impact of alcohol exposure. Many women who consume alcohol during pregnancy use other drugs such as cocaine and marijuana. However, very little data on the effects of poly-drug use exist (Morse 1993).

Given that so many variables influence the effect of alcohol on a fetus and that no safe level of alcohol consumption during pregnancy has been established, a policy of abstention from drinking is widely recommended.

Given that so many variables influence the effect of alcohol on a fetus and that no safe level of alcohol consumption during pregnancy has been established, a policy of abstention from drinking is widely recommended. In 1981 the U.S. Surgeon General issued an advisory that states: "The Surgeon General advises women who are pregnant (or considering pregnancy) not to drink alcoholic beverages and to be aware of the alcoholic content of foods and drugs." More recently, Congress enacted legislation that requires warning labels on all alcoholic beverages, one of which addresses the dangers of drinking during pregnancy and recommends abstention. Evidence indicates that such public information efforts are needed to increase understanding of the dangers of drinking alcoholic beverages during pregnancy. In the 1985 National Health Interview Survey's Health Promotion and Disease Prevention Study, only 55% of the 20,000 respondents age 18-44 had ever heard of FAS, and of those who had, less than one quarter correctly identified it as a set of birth defects. Seventy one

percent thought it meant being born addicted to alcohol. In addition, heavier drinkers perceived less risk and had heard of FAS less often than light to moderate drinkers (Fox 1987).

Meanwhile, data on alcohol consumption indicate that many pregnant women and women of childbearing age consume alcoholic beverages and, thus, are at-risk for having children with FAS or other alcohol-related birth defects unless they modify their behavior during pregnancy.

- Data from the 1988 Alcohol Supplement of the National Health Interview Survey indicate that of the 52 million women in the United States age 18-44, 1.7 million consumed 2 or more drinks per day. These women of childbearing age were at risk, therefore, of prenatally exposing the fetus to alcohol (NIAAA 1993).
- In the 1991 Behavioral Risk Factor Surveillance System survey, 1,067 women reported being pregnant at the time of the interview. Of those, 14 (1.3%) reported binge drinking (five or more drinks on at least one occasion during the preceding month). A total of 143 (13.4%) reported light drinking (30 or fewer drinks during the preceding month); 3 (0.3%) heavy drinking (60 or fewer drinks during the preceding month); and 1 (0.1%) moderate drinking (31-59 drinks during the preceding month) (CDC 1994).
- As many as 86% of women drink at least once during pregnancy, and experts estimate that between 20-35% of pregnant women drink regularly. In a 1989 study of 2,278 highly educated women (39% had postgraduate degrees), 30% consumed more than one drink per week during pregnancy (Rosenthal 1990).

What are the Implications for Educating Children Born with FAS/FAE?

Because damage caused by alcohol occurs along a continuum from mild to severe, each child with alcohol-related birth defects has a unique set of abilities and difficulties. These are manifested in cognitive, behavioral and physical characteristics that endure throughout the life of the affected individual. In order to help FAS/FAE children reach their potential, it is important to understand that they have a physiologically-based disability, to acknowledge the resulting cognitive and behavioral limitations, and to seek strategies for educating them that take these factors into account.

Because damage caused by alcohol occurs along a continuum from mild to severe, each child with alcohol-related birth defects has a unique set of abilities and difficulties. These are manifested in cognitive, behavioral and physical characteristics that endure throughout the life of the affected individual.

While growth and physical problems characterize children with FAS, the problems caused by central nervous system damage and resulting behavior dysfunction are the most serious (Smithells 1979). In fact, Streissguth & Randels (1988) found that maladaptive behavior, rather than limited intelligence, was the most handicapping disability for a group of FAS/FAE patients ages 12-42 and concluded that behavioral problems, based on inadequate or faulty thinking, were the basis of their lifelong disabilities. Indeed, although IQ scores for individuals with FAS and FAE span a broad range, identifiable behavioral problems are consistently evident in those with alcohol-related birth defects.

General developmental characteristics of children with FAS/FAE correlate with age. This has important implications for educational and other intervention strategies.

Infancy

Infants with FAS/FAE are usually small for height and weight. They are irritable and tremulous, cry excessively, overreact to sounds, sleep poorly and have poor muscle tone (Smitherman 1994). They also may have more difficulty habituating or getting used to stimulation in their environment. Failure to thrive is commonly observed, and some infants have seizure disorders or congenital deficits (Smitherman 1994).

Preschool Years

At this stage, children with FAS/FAE are often alert, talkative and friendly, making them seem more competent and skillful than they actually are (Olson, Burgess et al. 1992). At the same time,

however, they have deficits such as short attention spans, distractibility, clumsiness and hyperactivity. Some have severe temper tantrums, and developmental delays are common (Smitherman 1994). Researchers have also found a high incidence of hearing disorders among children with FAS, which may account, in part, for the high rate of language delays and speech deficits they experience (Church & Gerkin 1988).

Middle Childhood

FAS/FAE children are often characterized by hyperactivity, distractibility, impulsivity and memory difficulties. They are usually affectionate and interested in those around them, but lack social skills for making friends and avoiding strangers. In school they often have trouble making transitions and predicting the consequences of their behavior. In the primary grades, these children's developmental deficits may result in academic problems. Their tendency toward concrete thinking interferes with learning abstract concepts, especially in the area of mathematics (Olson, Burgess et al. 1992). They may appear more competent than they actually are, leading teachers to overestimate their abilities and conclude that they are lazy or stubborn (Blume 1992).

Adolescence and Adulthood

FAS/FAE endure throughout the life of the affected individual. Following puberty, the characteristic facial features and growth deficiency of individuals with FAS/FAE are less apparent, although they usually remain short in stature and have small head size. They have limited reasoning and judgement abilities, which leads many to characterize them as having "poor judgement." Adolescents with FAS may act impulsively, repeat mistakes, and fail to consider consequences. They use time poorly and seek immediate gratification. They also have deficits in abstract thinking. These limitations mean that the adolescent with FAS/FAE needs the same intensity of supervision as a much younger child and that most adults with FAS/FAE are unable to hold jobs or live independently (Smitherman 1994).

Given these developmental patterns, it is not surprising that children with FAS/FAE have special educational needs. While many people have a learning disability in one or two areas, children with FAS have processing deficits in all areas caused by central nervous system dysfunction. They have difficulty recording, interpreting, storing, retrieving and using information (Morse 1993), which affects both their cognitive and behavioral perform-

ance. Many teachers and parents have accused children with FAS/FAE of voluntarily exhibiting behaviors such as forgetfulness or repeating mistakes, when such behaviors are actually the result of CNS damage. This is especially true in the case of children with FAS/FAE whose IQs fall within the average or higher range. Thus, in order to accommodate the diverse needs of children with FAS/FAE, interventions must address their intrinsic cognitive and behavioral deficits.

Prevention and Intervention Strategies

Reducing the toll that FAS and FAE take on society and its women, children, and families requires a two-pronged approach: prevention and intervention. Although no cure exists for FAS/FAE, they are totally preventable. Moreover, evidence indicates that some interventions can reduce the impact of FAS/FAE on those already affected. Although prevention and intervention efforts are limited in number, those that do exist provide important lessons and point to key factors that can help prevent and/or ameliorate the consequences of these birth defects.

National Organization on Fetal Alcohol Syndrome (NOFAS)

1815 H Street, NW, Suite 710, Washington, DC 20006
202/785-4585, Patti Munter, Executive Director

The National Organization on Fetal Alcohol Syndrome (NOFAS) is a non-profit organization committed to raising public awareness about FAS and FAE. It seeks to implement innovative ideas in prevention, intervention, and advocacy, and takes a multicultural approach. Its numerous campaigns include developing the first medical school curriculum on FAS for first and second year medical students; establishing a national information clearinghouse on FAS/FAE; launching bilingual public information campaigns in several states; producing public service announcements; publishing children's books on the importance of not drinking during pregnancy; holding national conferences on FAS; and working with the Indian Health Service to form the first national task force on FAS.

Strategies for Women

Clearly, the most straight-forward way to prevent alcohol-related birth defects is to change the drinking behavior of pregnant women. Since no safe level of drinking has been established, the U.S. Surgeon General and others have recommended that women who are pregnant or considering pregnancy abstain from all alcoholic beverages. In order to ensure that all women of childbearing age and their families are aware of this important information, efforts are needed to provide all women of childbearing age with universal access to educational, health, and alcohol and other drug treatment services.

Efforts are needed to provide all women of childbearing age with universal access to educational, health, and alcohol and other drug treatment services.

Educational campaigns, particularly those that target health care providers, pregnant women, women of childbearing age, and the wider community can be effective avenues for getting the word out. It is also important to target men, since husbands, significant others, and family members can influence a woman's decision about drinking during pregnancy (Blume 1992). Such educational campaigns can range from public service announcements in the media to dissemination of informational materials at supermarkets, laundromats and other community sites. Indeed, studies have found that community education programs can be effective in modifying drinking behavior especially among social drinkers (NIAAA 1993). Education about the risks of drinking during pregnancy should also be an integral part of obstetrical and gynecological care for all women.

When it comes to problem drinkers, however, education is not enough. These women often need assistance in changing their drinking behavior, including intensive, individualized, and appropriate treatment. There is very little information available about the number of women in their childbearing years who seek treatment for alcoholism and what proportion in need receive it. However, women are underrepresented in alcohol and other drug treatment programs due, in large part, to the many barriers that stand between them and the care they need. These include failure to identify women with alcohol problems because they tend to fall outside of the health and social service systems or because health care professionals are not sufficiently trained to recognize alcohol problems and make referrals; lack of comprehensive programs that meet the special needs of alcohol-dependent pregnant women; logistical barriers such as waiting lists, lack of transportation, and child care; insurance/financial difficulties; and women's fear of incarceration and/or of having their other children placed in foster care if they seek treatment.

Research on treatment programs for alcohol-dependent pregnant women have focused almost exclusively on those that address poly-drug use and have found that such services are rarely avail-

able for pregnant women. In both 1989 and 1990, states reported that only about 11% of the pregnant women estimated to need services were in treatment (NASADAD 1990). The primary reason is that few programs accept pregnant women, particularly those who are poor or have public insurance (Regan 1987). In a survey of drug treatment programs in New York City, pregnant addicted women were refused service by 54% of 78 programs (Chavkin 1989). A study by the Southern Regional Project on Infant Mortality of four sites in the South found that 53% of treatment programs had waiting lists and 25% of pregnant or parenting women had been unable to find space in a program in the past. Moreover, 79% of treatment programs were not reimbursed for services by Medicaid, while 61% of women interviewed were insured by Medicaid. This study also found that fears of medical liability often made it difficult for treatment programs to recruit physicians to treat pregnant women addicted to alcohol and other drugs since they are considered to be high-risk (Gehshan 1993). It is not surprising, therefore, that even the most determined women are likely to have trouble gaining access to treatment.

Despite the shortage of programs that treat alcohol and other drug-dependent pregnant women, evidence suggests that these programs can be effective. A recent Institute of Medicine commission that examined the effectiveness of substance abuse treatment concluded that treatment for pregnant women appears to be as effective as for other adult clients (Institute of Medicine 1990). Moreover, studies have shown that pregnant women in treatment for alcohol and other drug use have better birth outcomes than those without interventions (Hill 1993).

Growing concern about alcohol and other drug use among pregnant women has resulted in a variety of federal, state, and local level efforts to assess the extent of such problems and to address them. Within the U.S. Department of Health and Human Services, the primary responsibility for public education to prevent alcohol problems belongs to the Center for Substance Abuse Prevention (CSAP). In addition to developing media campaigns, CSAP awards grants for the establishment of model projects for prevention, education, and treatment for alcohol and other drug addiction for pregnant and parenting women and their children (Anderson 1992). Congress passed the Anti-Drug Abuse Act of 1988 (PL 100-690) which included authorized funds for demonstration projects for substance using pregnant women and their children. More recently, legislation was introduced in Congress to help prevent FAS/FAE by facilitating access to treatment programs for alcohol and other drug dependent pregnant women and their children through the establishment of demonstration projects and through Medicaid expansions to cover such treatment (see box).

According to a report by the National Governors' Association, as of 1991, 44 states had formed special task forces or work groups to study women's use of substances during pregnancy and its implications for mothers and children. These work groups have found that an effective response must draw upon the expertise and resources of numerous state agencies and programs including Medicaid, maternal and child health, alcohol and drug abuse, and child welfare. Several states have taken steps to implement innovative initiatives. These include conducting needs assessments, stressing prevention and treatment over punitive responses, expanding the number and accessibility of residential treatment beds for women and their children, reducing logistical barriers to care, enhancing case management and providing early intervention and parenting education services to intervene on behalf of substance exposed infants (Hill 1993). Despite these encouraging efforts, much work remains to be done to meet the needs of alcohol and other drug dependent pregnant women and their children.

The Medicaid Substance Abuse Treatment Act of 1993

"The Medicaid Substance Abuse Treatment Act of 1993" (S. 484), introduced by Senators Tom Daschle (D-SD) and Bill Bradley (D-NJ), seeks to improve access to alcohol and other drug treatment programs for low-income pregnant women. This legislation would create a new option under Medicaid for states to cover non-hospital comprehensive residential substance abuse treatment services for Medicaid-eligible, pregnant, addicted women and their children. Due to higher rates of alcoholism among Native American women, the bill also allocates additional beds to each Indian Health Service Area in the country. In order to receive reimbursement, a residential treatment facility would have to provide a comprehensive set of rehabilitation and health services specifically designed to address the needs of pregnant, addicted women such as counseling, parenting skills training, room and board, and therapeutic child care. Children may accompany mothers while they are in treatment. This bill is in the Finance Committee, and discussions are underway about the possibility of including various components in a health care reform proposal.

Strategies for Children and Families

Efforts to intervene on behalf of those already affected by FAS/FAE have taken a backseat to attempts to prevent these syndromes in the first place. This is particularly true in regard to programs designed to educate children with FAS/FAE. Nevertheless, those spearheading and evaluating existing initiatives have identified key strategies that work and suggest that "a diagnosis of FAS or FAE does not carry an inevitable sentence of school failure, a jail term, or any other outcome" (Kleinfeld 1993).

Responding to the diverse cognitive, behavioral, and medical needs of FAS/FAE individuals is no easy task, and no single parent, teacher, or community service can be expected to do it all. These representatives must work together in a coordinated effort to become advocates for children with FAS/FAE.

Infants and Children

It is widely agreed that intervention with FAS/FAE children should begin as early as possible and continue throughout their lives.

It is widely agreed that intervention with FAS/FAE children should begin as early as possible and continue throughout their lives. Key to appropriate early intervention for children with FAS/FAE are developing and maintaining realistic expectations; thinking long-term; learning to reframe child behaviors; and keeping an open mind about goals and strategies for working with children and families (Olson, Burgess et al. 1992). Identifying FAS/FAE early enables interventionists to tailor assistance to meet the needs of both the child and the family. Early casefinding can also help avoid the frustrations inherent in rearing a child with undiagnosed FAS/FAE (Smitherman 1994).

For infants, the most important initial intervention is enrollment in a high-risk infant monitoring system that follows the child's developmental progress, home environment, and health. Infancy is a good time to build a service network that can support and supplement parents' care (Olson, Burgess et al. 1992). Infants with FAS may benefit from early infant stimulation programs, which can offset some developmental delay. This is particularly important for children who are not receiving adequate stimulation in the home. Various programs are available, and in some locales eligibility for medical assistance may include free classes (Giunta 1988). Established principles of therapeutic child care have also been applied to early intervention programs serving young children with FAS/FAE. These include insuring a low staff-child ratio, changing the environment to help structure the child, and setting up daily routines (Olson, Burgess, et al. 1992). According to Maureen Murphy, a specialist in multihandicapped education who has worked with many alcohol-affected children and their families, "the cornerstone of educating an infant with

FAS/FAE is to locate activities that prevent the child from becoming over or understimulated — mentally and physically. The need for sensory input can be adapted to the child's level of functioning with constant intervention" (Murphy 1993). She has found that infants who participate in a program that helps them to increase their tolerance to touch and noise make a smoother transition to formal schooling than those infants with FAS/FAE who do not.

Developmental delays and delays in acquisition of language skills are often first detected among preschoolers with FAS. Children with FAS/FAE need special preschools that emphasize structure and routine and focus on skills such as speech development. They do best in schools where teachers provide consistent supervision, routines are clear and unvarying, classroom spaces are clearly marked, and visual information supplements verbal directions. (Tanner Halverson 1993). The mental and social stimulation of preschool may help attenuate some developmental problems experienced by individuals with FAS/FAE (Giunta 1988). Preschool teachers who know how to identify FAS-related deficits can refer children for diagnosis and psychological testing and individualized educational planning can begin for the child. Although it is not known how many child care providers are trained to recognize indicators of prenatal alcohol exposure, some states' child care licensing regulations require the use of a curriculum that includes such training for certification.

Placement of children with FAS/FAE in special education classes is often necessary by the time they reach elementary school. In a regular classroom, these children's short attention spans and distractibility may compound their intellectual deficits

Placement of children with FAS/FAE in special education classes is often necessary by the time they reach elementary school. In a regular classroom, these children's short attention spans and distractibility may compound their intellectual deficits (Tanner Halverson 1993). A small classroom setting with clear guidelines and a great deal of individual attention to students can help these children maximize their intellectual capabilities and modify some of their behavioral problems (Tanner Halverson 1993). However, simply placing children with FAS/FAE in programs for the mentally handicapped may not be sufficient, since such programs tend to be designed for patients with other disabilities, such as Down's Syndrome, who may have very different needs than children with FAS/FAE (Rosenthal 1990).

Children with FAS/FAE differ in their cognitive and behavioral abilities. Even children with FAS/FAE who have higher IQs suffer from behavioral deficits that result in hyperactivity, learning disorders, and difficulties adapting. Studies have found that those with normal IQs have difficulty in both classroom management and learning due to CNS impairments (Gold 1984).

Shaywitz (1981) found that alcohol exposed children with intelligence in the average range (82-113 IQ) experienced persistent academic failure. This finding indicates that even those children with the least severe cases of FAS and FAE need programs that address their unique needs. However, many FAS children have IQ scores above 70, the frequent cutoff point for eligibility for special community services (Streissguth et al. 1991). Other factors also affect eligibility for special services.

While many children ages 0-2 qualify to receive early intervention services through Part H of the Individuals with Disabilities Education Act (PL 99-457), and older children may qualify for special education services, many children with FAS/FAE may not be served by either. Children who are not diagnosed with FAS or FAE or who have some level of alcohol-related birth defects but are not considered developmentally delayed, or who live in states that have not opted to cover infants and toddlers at-risk of developmental delays may not receive the interventions they need.

While educational programs for children with FAS/FAE are rare, some have developed techniques that parents and teachers can use to educate alcohol-affected children. The common thread is simplifying the information that the child must process at any one time by creating structured, routine environments (Kleinfeld 1993). One promising initiative designed to meet the specific needs of FAS children is a special education class for FAS/FAE children in Arizona (see box). This program is couched in the understanding that, for children to learn, a teacher must gain and hold their attention. Thus, one major focus of the project is addressing the difficulty children with FAS/FAE have maintaining attention and related behaviors such as hyperactivity, distractibility, and impulsivity. A second major focus of the program is to empower students and their communities with a sense of identity by including cultural components in the educational program. The program director and staff have found the keys to working successfully with children with FAS/FAE are structure, consistency, brevity, variety, and persistence. A third component addresses behavioral objectives and social skills training. Unfortunately, few if any other school districts offer this kind of special program for educating children with FAS/FAE (Tanner Halverson 1993).

Adolescents and Adults

Recognizing that FAS and FAE endure throughout a person's lifetime, special education strategies must also focus on adolescents and adults. In a study of the impact of FAS/FAE in 61 adolescents and adults, researchers found their average academic functioning to be at a 2nd to 4th grade level. The older individuals did not generally function better academically than the younger

Cross/Categorical Special Education Classroom

Patricia Tanner Halverson, Ph.D., FAS/FAE Project Director
P.O. Box 248, Sells, AZ 85634, 602/299-9653

The purpose of this program is to identify methods and strategies that work to increase academic success and improve social skills and behavior for children with FAS/FAE. The project has several components: cultural awareness, getting and maintaining attention, behavioral control of the children, and social skills training. The program initially served children between 6 and 9 years old (who are now 10-13), all of whom are of relatively normal intelligence with IQs between 80 and 100.

The program is built on the belief that structure, consistency, brevity, variety, and persistence are essential for working successfully with children with FAS/FAE. Special strategies are used to teach organizational skills, increase attention, control impulsivity, deal with hyperactivity, exercise discipline, and improve memory. For example, the classroom is carefully structured to minimize sensory overload and promote routines; staffing is consistent; assignments involve short tasks with clearly defined objectives; exercises are used to increase children's attention spans; and physical and manual activities are encouraged to counteract hyperactivity. The project's children now do well in many mainstreaming activities with other students and have improved in math and reading skills. The program's director is convinced that many of the effects of prenatal exposure to alcohol can be ameliorated.

ones. Of the study population, only 6% were in regular classes without supplemental help, while 28% were in special education classes. Maladaptive behavior was common among them (Streissguth et al. 1991). The cognitive and behavioral limitations generally associated with FAS/FAE can translate into problems for adolescents and adults in handling daily responsibilities. A study of 61 teenagers and young adults with FAS/FAE found that only one could handle money, none could manage a checking account, only one was employed full-time and none was self-supporting (Streissguth, LaDue, et al. 1988). Adding a basic life skills and/or vocational training component to a special education curriculum could improve the likelihood that this population could be more self-sufficient and live independently.

Families

Interventions on behalf of children and youth with FAS/FAE must address not only their needs, but their families' needs as well. Families need to learn how to cope with the demands of raising a child with FAS/FAE, and how to become advocates for their child.

Interventions on behalf of children and youth with FAS/FAE must address not only their needs, but their families' needs as well. Families need to learn how to cope with the demands of raising a child with FAS/FAE, and how to become advocates for their child. What happens in the home has an enormous impact on what happens to children with FAS/FAE. According to Jan Hinde, who has worked with alcohol-affected children for more than ten years, "children who remain in their natural homes vary the most in their progress. Some families are able to make changes, but others, deep into denial and the disease of alcohol, do not have the power to give the children care and intelligent attention. Alcohol-affected children placed in temporary foster homes or foster-adoptive homes also have problematic outcomes. Moving children from one home to another harms all children but especially hurts alcohol-affected children who need ... predictable routines" (Hinde 1993).

Parents of children with FAS or FAE may be struggling with alcohol addiction. One result is that the average child with FAS/FAE lives with its birth mother less than four years (Streissguth, LaDue, et al. 1988). In a study of adolescents and adults with FAS/FAE, Streissguth et al. (1991) found that only 3% lived with their biological mothers, and all study participants had lived, on average, in five different principal homes in their lifetimes. This is particularly troubling, given that "children with prenatal alcohol damage do best in stable, predictable, nurturing home environments where they receive intense attention" (Hinde 1993).

Interventions can also focus on helping parents or caretakers cope with and become teachers and/or advocates for their children. Although strategies will change as the child grows older, experts have offered general guidelines for creating a positive home environment. These include developing family routines and undertaking one activity at a time to minimize distractions (Hornby 1993). Parents can be taught to use many techniques to build their children's attention span, reduce their sensitivity to touch, and teach them how to play in productive and educational ways (Kleinfeld 1993). Interventions also include teaching parents how to be advocates for their children and how to get what they need from the school system and other community resources.

Most of the innovative programs implemented to educate children with FAS and FAE have originated at the local level. However, at the federal level, a few related initiatives can be identified. For example, the Administration for Children, Youth and Families in the U.S. Department of Health and Human Services funds

Comprehensive Fetal Alcohol Syndrome Prevention Act

"The Comprehensive Fetal Alcohol Syndrome Prevention Act" (S. 1821), introduced by Senator Tom Daschle (D-SD), Senator Jeff Bingaman (D-NM) and 12 co-sponsors, would establish a comprehensive program to prevent FAS/FAE across the nation. It would coordinate and support national and targeted public awareness, prevention, and education programs on FAS/FAE; coordinate and support applied epidemiologic research concerning FAS/FAE; disseminate FAS/FAE diagnostic criteria to health care and social service providers; and foster coordination among all federal agencies that conduct or support FAS/FAE research. This program would be coordinated by the U.S. Department of Health and Human Services. The bill is awaiting consideration by the Senate Labor and Human Resources Committee.

projects including child welfare research and demonstration grants that address the needs of substance-affected infants and boarder babies (Hill 1993). U.S. Senator Tom Daschle has introduced "The Comprehensive FAS Prevention Bill" which would establish a multi-part program to address the needs of FAS children and their families (see box). Nevertheless, much more needs to be done at the federal, state, and local levels to support and enhance activities targeting children and families touched by FAS/FAE.

Recommendations

The Broken Cord, written by Michael Dorris in 1989, is a landmark book that has raised the nation's awareness about the dangers of drinking during pregnancy by describing the fate of his alcohol-exposed, adopted son, Adam. Since the publication of the book, Dorris has continued to be an outspoken and powerful advocate for policies and programs that prevent FAS/FAE and that address the needs of children and families already struggling with the consequences of alcohol-related birth defects. In recent Congressional testimony, Dorris stated that:

> *Each person must play a role. Scientists can study the biochemistry involved in fetal damage from drugs; advocates and politicians can address prevention; social workers, psychologists, and educators can tackle the needs of the here-and-now. We can devise effective curricula, learning regiments, humane models for dependent care.*

Indeed, it is clear that efforts to curtail and ameliorate FAS and FAE are not the responsibility of any single entity. The roots and consequences of FAS/FAE are so diverse that they demand action by families, educators, health professionals, researchers, policymakers, and others. Collaboration and cooperation are essential to developing prevention and intervention strategies that can make a meaningful difference for women, children, and families nationwide. Below are examples of action steps that can be taken to bolster current efforts to combat FAS/FAE. While the list is by no means exhaustive, it provides a starting point from which work can begin on several fronts to address this critical health and education problem.

General Recommendations

- Promote public education about the risks of drinking during pregnancy, including a clear message about the importance of abstaining from all alcoholic beverages. Emphasize that FAS/FAE are totally preventable.
- Improve tracking and epidemiological methodology for collecting data on the incidence and prevalence of FAS/FAE.
- Pursue research to increase understanding about FAS/FAE, including the mechanisms through which they occur and the role of factors such as dose and timing of alcohol consumption during pregnancy.

- Include comprehensive health insurance coverage for alcohol and other drug dependency prevention and treatment services in any national health care reform plan.
- Increase federal appropriations for health and education programs targeted specifically for FAS/FAE prevention and intervention.
- Encourage state and local governments to make prevention and intervention of FAS/FAE top priorities.
- Conduct evaluations of special programs for children with FAS/FAE to identify the key components that are responsible for positive outcomes.

Recommendations Targeting Women

- Ensure all women have access to early, regular, and comprehensive prenatal care.
- Make education about and screening for alcohol problems a core part of obstetric and gynecologic care.
- Enhance access to comprehensive, appropriate, affordable treatment for alcohol and other drug-dependent pregnant women.
- Provide child care at all alcohol and other drug treatment sites.
- Encourage networking among private physicians, prenatal clinics, pregnancy support centers, prenatal classes, maternal infant care centers, family planning programs, alcohol and other drug treatment centers, and others that serve pregnant women or women planning pregnancies.
- Provide Medicaid reimbursement for comprehensive, non-hospital residential treatment services for pregnant women and their children.
- Refrain from using punitive measures to address alcohol and other drug use during pregnancy. Punitive measures may deter pregnant, addicted women from seeking help and fail to get at the real problems, such as lack of access to treatment programs.
- Establish cooperative agreements at the federal and state levels among alcohol and other drug agencies and maternal and child health agencies to ensure appropriate identification, referral, and care for pregnant women and their children.

Recommendations Targeting Children

- Provide education for health care and child care professionals about the prevention and treatment of FAS/FAE, including strategies for patient education, training in diagnosis, and information on making referrals.
- Provide children with FAS or FAE with a comprehensive evaluation that will allow both parents and professionals to establish realistic educational goals.
- Begin intervention efforts with FAS/FAE infants/children as early as possible.
- Increase the number and availability of health, education, and support systems to serve FAS/FAE-affected children from infancy and throughout their lives.
- Provide teachers with training and information about the impact of FAS/FAE on children so they can better recognize and respond to their needs.
- Provide training in effective techniques for working with children with FAS and FAE for parents, teachers, and community program personnel.
- Change the eligibility criteria so that children can qualify for special programming based on the diagnosis of FAS/FAE, not only on IQ.

Conclusion

Experiences in prevention and intervention indicate that much can be done to prevent FAS and FAE and lessen their toll when they do occur. Clearly, preventing FAS/FAE through public education and accessible and appropriate treatment for alcohol and other drug-dependent pregnant women is one way to help ensure that all children are born healthy in the first place. Short of that, the importance of carefully structured intervention programs for children with FAS/FAE cannot be overemphasized.

Early and continuous educational, behavioral, and psychosocial interventions that address the comprehensive needs of FAS/FAE children and their families can help ensure that they reach their full potential. Currently, we are a long way from that goal. Education and community programs tailored for children with FAS/FAE are few and far between. Even when they do exist, the children who need them are often bypassed due to failure to recognize that they have alcohol-related birth defects or because they do not qualify for services based on present criteria.

Children with FAS/FAE are not a doomed population. As described in this paper, many educators and advocates who work with this population have witnessed encouraging cognitive and behavioral improvements resulting from innovative intervention efforts. A coordinated, concerted effort by educators, policymakers, parents, researchers, health professionals, and others is needed to make the health, education, and well-being of children with FAS/FAE a national priority.

The National Health/Education Consortium and the Children of Alcoholics Foundation believe that children's health and ability to learn are inextricably linked. FAS and FAE provide a striking example of that relationship and serve as a strong reminder of how a child's ability to learn can be affected long before he or she enters school.

10 Common Misconceptions About Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE)

1. FAS means mental retardation.

- *Some* people with FAS are mentally retarded, others are not.
- People with FAS *can* have normal intelligence.
- People with FAS are brain damaged and have specific areas of strengths and weaknesses. It is similar to people who have sustained brain injury from an auto accident.

2. The behavior problems associated with FAS/FAE are the result of poor parenting or a bad environment.

- Being brain damaged can lead to behavior problems because brain damaged people don't process information the same way that other people do, so they don't always behave as others expect them to.
- Brain damaged children can be hard to raise in the best environment.
- Parents of children with FAS/FAE need help and support, not criticism.

3. People with FAS/FAE will outgrow their behavior problems as they mature.

- Unfortunately, they do not. FAS lasts a lifetime, but the way the individual behaves and the type of problems he/she exhibits can change with each age.
- It takes a longer period of sheltered living for brain damaged children to "grow up."

4. To admit people with FAS/FAE are brain damaged is to give up on them.

- Have we given up on children with other birth defects? No!
- We need continuing research to understand the needs of patients with FAS and how to help them. We will learn how to help them when we decide to invest money and energy into research on this problem.

5. Diagnosing people with FAS/FAE will label them for life.

- A diagnosis tells you what the problem is, helps you figure out how to treat the problem, and relieves the person with FAS/FAE of having to meet unrealistic expectations.

6. People with FAS/FAE are unmotivated when they don't keep appointments or act in a way that we consider irresponsible.

- Probably the explanation lies in memory problems, inability to problem-solve effectively, or simply being overwhelmed.
- Sometimes people with FAS/FAE misconstrue reality.

7. One agency alone can solve any or all of the problems associated with people with FAS/FAE.

- The multiple needs of patients with FAS/FAE require multiple fronts of intervention and intense inter-agency cooperation.

8. The numerous problems in dealing with the reality of FAS/FAE will be solved with existing knowledge.

- Ongoing research is desperately needed, and the magnitude of the problem will make it necessary and compelling to do so.

9. The problem of FAS/FAE will go away.

- FAS is 100% preventable, but alcohol is so much a part of our culture and so aggressively marketed to those least able to resist, that active prevention activities must continue on all fronts to safeguard our children's future and the future of our people.

10. Women have an easy choice not to drink during pregnancy and, through callousness or indifference, permanently damage their children.

- Biologic mothers of children with FAS need help with their alcoholism and/or with birth control.
- Pregnancy is an excellent time for alcohol-abusing women to stop drinking, but they need our help.

From Ann Streissguth and the *Iceberg* Editorial Board; Spring 1993, p. 6.
Reprinted with permission from *Iceberg*, P.O. Box 95597, Seattle, WA 98145-2597.

Resources for Additional Information on FAS and FAE

Boston University Medical Center
Fetal Alcohol Education Program
7 Kent Street
Brookline, MA 02146
Telephone: 617/739-1424

Center for Substance Abuse Prevention (CSAP)
National Resource Center
9300 Lee Highway
Fairfax, VA 22031
Telephone: 703/218-5600 or 1/800-354-8824

Children of Alcoholics Foundation
P.O. Box 4185 Grand Central Station
New York, NY 10163
Telephone: 212/754-0656 or 1/800-359-COAF

Fetal Alcohol & Drug Unit
University of Washington, School of Medicine
2707 NE Blakeley
Seattle, WA 98195
Telephone: 206/543-7155

National Organization on Fetal Alcohol Syndrome (NOFAS)
1815 H Street, NW, Suite 710
Washington, DC 20006
Telephone: 202/785-4585 or 1/800-66-NOFAS

National Clearinghouse for Alcohol and Drug Information (NCADI)
P.O. Box 2345
Rockville, MD 20852
Telephone: 301/468-2600 or 1/800-729-6686

National Association for Perinatal Addiction Research and Education (NAPARE)
200 N. Michigan Avenue, Suite 300
Chicago, IL 60601
Telephone: 312/541-1272

National Council on Alcoholism and Drug Dependence (NCADD)
12 W. 21st Street
New York, NY 10010
Telephone: 212/206-6770

References

Abel, E., *New Literature on Fetal Alcohol Exposure and Effects, A Bibliography 1983-1988*. Greenwood Press, New York, 1990. pp. ix-xii.

Abel, E., Incidence of Anomalies Among Siblings of FAS Cases. *Neurotoxicology and Teratology*, 10:1-2, 1988.

Abel, E. and Sokol, R.J., Fetal Alcohol Syndrome is Now Leading Cause of Mental Retardation. *Lancet*, 2:1222, 1986.

Abel, E. and Sokol, R.J., Incidence of Fetal Alcohol Syndrome and Economic Impact of FAS-Related Anomalies. *Drug and Alcohol Dependence*, 19(1):51-70, 1987.

American Academy of Pediatrics, Fetal Alcohol Syndrome and Fetal Alcohol Effects. *Pediatrics*, 91(5):1004-1006, 1993.

Anderson, B. and Novick, E., *Fetal Alcohol Syndrome and Pregnant Women Who Abuse Alcohol: An Overview of the Issue and the Federal Response*. U.S. Department of Health and Human Services, Washington, D.C., February 1992.

Blume, S.B., *What You Can Do to Prevent Fetal Alcohol Syndrome*. Johnson Institute, Minneapolis, MN, 1992.

Bonthius, D.J. and West, J.R., Alcohol-Induced Neuronal Loss in Developing Rats: Increased Brain Damage with Binge Exposure. *Alcoholism, Clinical and Experimental Research*, 14(1):107-118, 1990.

Centers for Disease Control and Prevention, Fetal Alcohol Syndrome — United States 1979-1992, *Morbidity and Mortality Weekly Review*, 42(17):339-341, 1993.

Centers for Disease Control and Prevention, Frequent Alcohol Consumption Among Women of Childbearing Age — Behavioral Risk Factor Surveillance System. *Morbidity and Mortality Weekly Review*, 43(18):328-335, 1994.

Chavkin, W., Testimony Presented to the House Select Committee on Children, Youth and Families, April 27, 1989.

Church, M.W. and Gerkin, K.P., Hearing Disorders in Children with Fetal Alcohol Syndrome: Findings from Case Reports. *Pediatrics*, 82(2):147-154, 1988.

Fox, S.M.; Brown, C.; Koontz, A.M.; and Kessel, S.S, Perceptions of Risks of Smoking and Heavy Drinking During Pregnancy: 1985 NHIS Findings. *Public Health Reports*, 102(1):73-79, 1987.

Gehshan, S., *A Step Toward Recovery*. Southern Regional Project on Infant Mortality, Washington, D.C., 1993.

Giunta, C.T. and Streissguth, A.P., Patients with Fetal Alcohol Syndrome and Their Caretakers. *Social Casework: The Journal of Contemporary Social Work*, September 1988, pp. 453-459.

Gold, S. and Sherry, L., Hyperactivity, Learning Disabilities, and Alcohol. *Journal of Learning Disabilities*, 17(1):3-6, 1984.

Hawks, S.R., Fetal Alcohol Syndrome: Implications for Health Education. *Journal of Health Education*, 24(1):22-25, 1993.

BEST COPY AVAILABLE

Hill, I.T. and Breyel, J.M., *Creating Systems of Care for Substance-Using Pregnant Women and their Children.* National Governors' Association, Washington, D.C., 1993.

Hinde, J., Early Intervention for Alcohol-Affected Children, in *Fantastic Antone Succeeds!* Kleinfeld, J. and Wescott, S. (Eds.), University of Alaska Press, 1993, pp. 131-147.

Hornby, R., Helping Families and Their Alcohol-Affected Children, in *Fantastic Antone Succeeds!* Kleinfeld, J. and Wescott, S. (Eds.), University of Alaska Press, 1993, pp. 273-294.

Institute of Medicine, *Treating Drug Problems, Volume 1: A Study of the Evolution, Effectiveness, and Financing of Public and Private Drug Treatment Systems.* Gerstein, I.R. and Harwood, H. (Eds.), National Academy Press, Washington, D.C., 1990, pp. 154-155.

Jones, K.L. and Smith, D.W., Recognition of the Fetal Alcohol Syndrome in Early Infancy. *Lancet*, 2:999-1001, 1973.

Jones, K.L.; Smith, D.W.; Ulleland, C.N.; and Streissguth, A.P., Pattern of Malformation in Offspring of Chronic Alcoholic Mothers. *Lancet* 1(7815)1267-1271, 1973.

Kleinfeld, J. and Wescott, S. (Eds.), *Fantastic Antone Succeeds! Experiences in Educating Children with Fetal Alcohol Syndrome.* University of Alaska Press, 1993.

Little, B.B.; Snell, L.M.; Rosenfeld, C.R.; Gilstrap, L.C.; and Gant, N.F., Failure to Recognize Fetal Alcohol Syndrome in Newborn Infants. *American Journal of Diseases in Children*, 144(10): 1142-1146, 1990.

May, P.A.; Hymbaugh, K.J.; Aase, J.M. and Samet, J.M., Epidemiology of Fetal Alcohol Syndrome Among American Indians of the Southwest. *Social Biology*, 30(4):374-387, 1983.

May, P.A., Personal Communication, June 1994.

Morse, B.A., Information Processing: Identifying the Behavioral Disorders of Fetal Alcohol Syndrome, in *Fantastic Antone Succeeds!* Kleinfeld J. and Wescott, S. (Eds.), University of Alaska Press, 1993, pp. 23-36.

Murphy, M., Shut up and Talk to Me, in *Fantastic Antone Succeeds!* Kleinfeld, J. and Wescott, S. (Eds.), University of Alaska Press, 1993, pp. 189-199.

National Association of State Alcohol and Drug Abuse Directors, *Survey of State Alcohol and Drug Agency Use of Fiscal Year 1989 Federal and State Funds.* Washington, D.C., 1990.

National Institute on Alcohol Abuse and Alcoholism (NIAAA), *Eighth Special Report to the U.S. Congress on Alcohol and Health.* U.S. Department of Health and Human Services, Washington, D.C., September 1993.

Newman, L.F. and Buka, S.L., Clipped Wings, *American Educator*, Spring 1991, pp. 27-42.

Olson, H.C.; Burgess, D.M.; and Streissguth, A.P., Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE): A Lifespan View, with Implications for Early Intervention. *Zero to Three/National Center for Clinical Infant Programs*, 13(1):24-29, 1992.

Olson, H.C.; Sampson, P.D.; Barr, H.; Streissguth, A.P.; and Bookstein, F.L., Prenatal Exposure to Alcohol and School Problems in Late Childhood: A Longitudinal Prospective Study. *Development and Psychopathology*, 4:341-359, 1992.

Osborn, J.A.; Harris, S.R.; and Weinberg, J., Fetal Alcohol Syndrome: Review of the Literature with Implications for Physical Therapists. *Physical Therapy*, 73(9):599-607, 1993.

Regan, D., Infants of Drug Addicts: At Risk for Child Abuse, Neglect, and Placement in Foster Care. *Neurotoxicology and Teratology*, 9:315-319, 1987.

Rice, D.; Kelman, S.; Miller, L.S.; and Dunmeyer, S., *The Economic Costs of Alcohol and Drug Abuse and Mental Illness:* 1985. U.S. Department of Health and Human Services, Public Health Service, Alcohol, Drug Abuse and Mental Health Administration, 1990.

Robinson, G.C.; Conry, J.L.; and Conry, R.F., Clinical Profile and Prevalence of Fetal Alcohol Syndrome in an Isolated Community in British Columbia. *Canadian Medical Association Journal*, 137(3):203-207, 1987.

Rosenthal, E., When a Pregnant Woman Drinks. *New York Times Magazine*, February 4, 1990, pp. 30-61.

Serdula, M.; Williamson, D.F.; Kendrick, J.S,: Anda, R.F.; and Byers, T., Trends in Alcohol Consumption by Pregnant Women: 1985 through 1988. *Journal of the American Medical Association*, 265(7):876-879, 1991.

Shaywitz, S.E.; Caparulo, B.K.; and Hodgson, E.S., Developmental Language Disability as a Consequence of Prenatal Exposure to Ethanol. *Pediatrics*, 68(6):850-855, 1981.

Smithells, R.W., Fetal Alcohol Syndrome. *Developmental Medicine and Child Neurology*, 21:244, 1979.

Smitherman, C.H., The Lasting Impact of Fetal Alcohol Syndrome and Fetal Alcohol Effect on Children and Adolescents. *Journal of Pediatric Health Care*, 8(3):121-126, 1994.

Sokol, R.J.; Ager, J.; Martier, S.; Debanne, S.; Ernhart, C.; Kuzma, J.; and Miller, S.I., Significant Determinants of Susceptibility to Alcohol Teratogenicity. *Annals of the New York Academy of Sciences*, 477:87-102, 1986.

Spohr, H.L.; Willms, J.; and Steinhausen, H.C., Prenatal Alcohol Exposure and Long-Term Developmental Consequences. *Lancet*, 341(8850):907-910, 1993.

Streissguth, A.P., Neonatal Effects of Alcohol Use, in Kinney, J., (Ed.), *Clinical Manual of Substance Abuse*. Mosby Year Book, 1991, pp. 202-206.

Streissguth, A.P.; Aase, J.M.; Clarren, S.K.; Randels, S.P.; LaDue, R.A.; and Smith, D.F., Fetal Alcohol Syndrome in Adolescents and Adults. *Journal of the American Medical Association*, 265(15):1961-1967, 1991.

Streissguth, A.P.; Clarren, S.K.; and Jones, K.L., Natural History of the Fetal Alcohol Syndrome: A 10-Year Follow-up of Eleven Patients. *Lancet*, 2(8446):85-91, 1985.

Streissguth, A.P.; LaDue, R.A.; and Randels, S.; *A Manual on Adolescents and Adults with Fetal Alcohol Syndrome with Special Reference to American Indians (2nd edition)*. Albuquerque, N.M.: Indian Health Service, 1988.

Streissguth, A.P. and Randels, S.P., Long-Term Effects of Fetal Alcohol Syndrome, in Robinson, G.C. and Armstrong, R.W., (Eds.), *Alcohol and Child/Family Health*. Vancouver, BC: University of British Columbia, 1988.

Tanner Halverson, P., Snagging the Kite String, in *Fantastic Antone Succeeds!* Kleinfeld, J. and Wescott, S. (Eds.), University of Alaska Press, 1993, pp. 201-222.

National Health/Education Consortium

Good health is a significant determinant of a child's ability to learn and succeed in school. The health and education sectors, however, have historically approached programs and services for children from different perspectives. Recognizing the need for better integration of health and education programs for children, the NATIONAL HEALTH/EDUCATION CONSORTIUM was organized in 1990 by the National Commission to Prevent Infant Mortality (NCPIM) and the Institute for Educational Leadership (IEL).

Housed at IEL, the project is unique in that it has brought together leaders from 59 national health and education organizations, representing some 12 million constituents, to bridge the gap between the worlds of health and education and to generate unified action for children. Promoting the full potential of children and providing them with the best opportunities for success will require changes in the systems which currently provide health and education services. Reforms are needed to develop more collaborative and cohesive policies and programs, unify agencies and funding streams, and provide a more comprehensive approach to children's problems.

Toward this end, the NATIONAL HEALTH/EDUCATION CONSORTIUM's activities focus on three major goals: to improve public policy by addressing the need for a better coordinated health and education delivery system; to strengthen communication and dissemination of information between health and education practitioners and policymakers; and to identify exemplary program models and practices which more effectively integrate health and education services. The Consortium involves educators, health professionals, policymakers, administrators, civic leaders, advocates, and parents in its efforts to bring together the health and education communities in a more integrated fashion.

The Consortium is able to attract high profile business, political, health and education leaders to give visibility to and implement its mission at the federal, state, and local levels. It does not represent any particular special interest group, but uniquely can mobilize the collective influence of national association consortium members on behalf of its mission. In addition, the consortium creates state and local networks across the country that will plant the seeds for similar collaborative efforts at those levels.

The foundation of the Consortium's efforts can be found in the report, *Crossing the Boundaries between Health and Education*, which documents clinical research and programs that exemplify the relationship between children's health and their learning potential. To complement this report, the Consortium releases a series of occasional papers and special reports focusing on various topics relating to health and education.

The NATIONAL HEALTH/EDUCATION CONSORTIUM is supported by The Prudential Foundation, the Honeywell Foundation, the AT&T Foundation, Metropolitan Life Foundation, and the Procter & Gamble Fund. Additional support has been provided by the U.S. Department of Health and Human Services, and the U.S. Department of Education.

For more information, please contact:

National Health/Education Consortium
c/o Institute for Educational Leadership
1001 Connecticut Ave, N.W., Suite 310
Washington, DC 20036
(202) 822-8405; Fax (202) 872-4050

National Health/Education Consortium Members and Profiles

American Academy of Family Physicians: 71,000 physicians

American Academy of Pediatrics: 45,000 pediatricians

American Association of Colleges for Teacher Education: represents 706 member institutions teacher education programs

American Association of School Administrators: 18,517 school administrators

American College of Nurse-Midwives: 3,500 certified nurse-midwives

American College of Obstetricians and Gynecologists: 31,000 obstetricians and gynecologists

American Dental Association: 140,000 dentists

American Federation of Teachers: 750,000 teachers, para-professionals (teacher aides), school-related personnel, healthcare workers, federal and state employees

American Hospital Association (MCH Section): 5,870 hospitals and physicians

American Indian Health Care Association: represents 36 programs and clinics which focus on the health care of American Indians

American Medical Association: 300,000 physicians

American Nurses Association: 201,000 registered nurses

American Psychological Association: 118,000 clinicians, researchers, educators, consultants, and students

American Public Health Association: 30,977 physicians, nurses, therapists, health technicians, health support personnel, and other health professionals

American School Food Service Association: 65,000 school food service professionals

American School Health Association: 4,000 health educations, nurses, physicians, and dieticians

American Speech-Language-Hearing Association: 74,000 speech-language pathologists, audiologists, scientists, researchers, and educators

Association for the Care of Children's Health: 4,200 nurses, child life workers, and parent leaders

Association for Supervision and Curriculum Development: 153,000 teachers, school administrators, college professors, and school board members

Association of American Medical Colleges: 126 U.S. medical schools, 450 teaching hospitals, and 92 academic professional societies

Association of Maternal and Child Health Programs: represents 269 maternal and child health programs in 50 states and U.S. territories

Association of Schools of Public Health: represents 14,500 deans, faculty, and students of schools of public health

Association of State and Territorial Dental Directors: represents 44 state and territorial dental directors

Association of State and Territorial Health Officials: represents the 58 health officers from each of the United States and its territories

Association of Women's Health, Obstetric, and Neonatal Nurses: 24,700 nurses

Council of Chief State School Officers: represents 56 public officials who head departments of elementary and secondary education in each state and extra-state jurisdiction

The Council of Great City Schools: represents 47 of the largest urban public school districts in the United States

Healthy Mothers, Healthy Babies Coalition: represents 95 non-profit health education groups, and state and local education groups

National Alliance of Black School Educators: 4,000 African-American teachers for Grades K-12

National Association for Asian and Pacific American Education: 594 members representing administrators, teachers, institutional aids, social workers, mental health workers, and students among others

National Association for the Education of Young Children: 77,000 members representing a wide range of early childhood professionals

National Association for Partners in Education: 55,000 volunteers, presidents and executives of private businesses, teachers, and administrators

National Association of Children's Hospitals and Related Institutions: represents 108 hospitals

National Association of Community Health Centers: represents 600 health care facilities

National Association of Elementary School Principals: 36,000 elementary school principals, middle school principals, school superintendents, teachers, professors, and instructors

National Association of Hispanic Nurses: 1,000 Hispanic nurses

National Association of Pediatric Nurse Associates and Practitioners: 4,200 pediatric nurse associates and practitioners

National Association of School Nurses, Inc.: 8,000 school nurses

National Association of Secondary School Principals: 41,000 secondary school principals, administrators, guidance counselors, activities directors, and college professors

National Association of Social Workers, Inc.: 145,000 members in all fields of social work

National Association of State Boards of Education: represents 600 state boards of education and their members

National Association of State School Nurse Consultants: 35 registered nurses employed at the state level in departments of education and/or health

National Association of WIC Directors: 624 state directors, nutrition coordinators, and local agency directors

National Black Nurses Association: 7,000 African-American nurses

National Coalition of Hispanic Health and Human Services Organizations: 12,000 organizations serving the Hispanic population, representing Hispanic physicians, nurses, and students

National Community Education Association: 1,600 teachers, superintendents, administrators, community education directors and coordinators, faculty and administrators of teacher education institutions and programs, community activists, private businesses, and state administrators

The National Congress of Parents and Teachers: 6.8 million parents, K-12 classroom teachers, principals, school administrators, and students

National Education Association: 2.1 million K-12 classroom teachers, professors, educational support personnel, and students

National Elementary School Center: represents 500 child-serving professionals

National Head Start Association: 150 nationwide agency members and 30 individual members

National Indian Education Association: 2,700 members, most of whom are Native American educators

National Medical Association: 16,500 minority physicians

National Mental Health Association: 550 local affiliate mental health associations representing mental health care providers, clients, and community health care centers

National Perinatal Association: 6,000 physicians, nurses, nurse-midwives, social workers, and consumers of perinatal services

National Rural Health Association: represents 2,000 community, migrant, and homeless health centers and their staffs

National School Boards Association: represents 52 state school board associations

National School Public Relations Association: 2,200 teachers, principals, administrators, retired teachers, students, and public relations personnel

Society for Neuroscience: represents 21,219 neuroscientists

Zero to Three – National Center for Clinical Infant Programs: represents 7,500 programs for high risk children and families, as well as individuals

This document does not necessarily reflect the viewpoints or positions of the Consortium's members.